

Testimony of
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Mr. Chairman and members of the Committee, thank you for the opportunity to testify here today. The Special Committee on Aging has played an important role in the discussion about the future of assisted living, raising questions about its definition, direction, quality of care and government regulation and the extent to which the interests of consumers and family members are protected. The Committee's interest created a vehicle for stakeholders to discuss and debate important issues.

The Committee extended a challenge to all stakeholders to reach consensus on standards for policymakers and regulators to consider as they develop state policy. Despite 18 months of hard work by numerous individuals, unanimous agreement was not possible but I doubt anyone expected it. The issues are complex, current policy is very diverse, and there is not enough research to determine what works best. There is consensus on many recommendations and strong reservations about several that received the required two-thirds vote for adoption.

The report includes all the recommendations that were considered by the Workgroup. The value of the report is its presentation of the recommendations, the rationale for them and the supplemental positions that present alternate views. Including the proposals that were not adopted gives readers a better sense of the approaches that may be considered and their implications. The array of issues and options will help states and stakeholders understand the issues and consider their own approach.

Recommendations

The recommendations and accompanying supplemental positions suggest that we are still unable to agree on what assisted living is, whom it should serve and how it should be regulated. State examples can be found that follow each recommendation and also the alternative, when one is described. The differences among stakeholders were evident in the recommendations describing the components of state oversight. A number of groups felt the recommendation gave more prominence to consumer decision-making over protection and safety. Consumers may not always have enough information about a facility to understand the risks to their health and safety and to make decisions about where and how care will be provided which suggests that regulations be more prescriptive. On the other hand, control and independence are important to quality of life and self-esteem. Systems that are flexible, offer choice and emphasize consumer decision-making are generally preferred by consumers. Consumer centered care is becoming the primary influence in the design of home and community based service programs. Both perspectives are important and it is difficult to find a balance, but balance is what I believe is needed.

Perhaps the most difficult issue is the starting point – what is assisted living? Examples of the recommended definition, and the suggested alternate definition, can be found among the definitions used by states. The recommended definition includes a philosophy and principles of assisted living that set the framework for developing standards and requirements that operationalize it. By itself, a philosophy does not specify the requirements for licensing, but it does serve as a benchmark for the design of rules governing admission and retention, services, staffing and training. Over half the states now include a philosophy of assisted living in statute or regulation. However, we do not have enough research that compares regulations to understand

how it works in practice and whether one approach or other has better outcomes.

One part of the recommended definition would require the use of at least two levels of licensing to differentiate facilities serving lower and higher need consumers. Again, both approaches have been implemented in states but general levels are more common. Ten states license facilities according to their level of care (Arizona, Arkansas, Idaho, Florida, Maine, Maryland, Mississippi, Missouri, Utah, and Vermont). The rest have a single level of care. The advantage of levels of care is that consumers know what to expect from each facility if they are required to provide all the services allowed for its level. The disadvantage is that residents may have to move when their care needs change. Maryland allows facilities to serve a percentage of residents that meet the criteria for the next level of care. Other states use waivers to allow a facility to retain a resident who no longer meets the retention criteria as long as they have the capacity to serve the resident and the resident, family and sometimes a physician agree. Single categories of care place greater importance on the resident agreement to clarify resident expectations. There is no basis for concluding that one approach works better than the other.

One of the many debates in assisted living is whether people who need nursing home care should be served and what the requirements should be if they do. Your position on this issue depends to some extent on your starting point. One starting point may be the services delivered by home health agencies and other providers to a person to help them remain in their single family home. Why shouldn't a person be able to bring services with them as they move from their single family home to an elderly apartment building or a licensed assisted living facility?

If your starting point is a nursing home and the regulatory environment in which services are delivered, you ask why don't we apply the same regulations to settings that provide similar services to the same people?

There are two important variables. It is important to understand who nursing homes serve now and the minimum criteria states use to decide who can enter a nursing home. State level of care criteria vary considerably. States that base the minimum threshold on impairments in activities of daily living historically have found significant percentages of people living in nursing homes who did not need to be there even though they qualify. With the expansion of Medicaid home and community based services waiver programs and assisted living, people have more options and fewer who need help with activities of daily living, medications and supervision are entering nursing homes. Statements in the report that say that assisted living serves people who qualify for admission to a nursing home should not be interpreted to mean that assisted living residents are comparable to the profile of current nursing home residents or are receiving 24 hour skilled care. It means that state criteria allow a broader mix of people to enter a nursing home than may actually live there. Allowing assisted living facilities to serve people who qualify for a nursing home does not mean they are all receiving the highest level of care available in a nursing home.

State Medicaid programs set criteria for admission to nursing homes that also apply to eligibility for Medicaid home and community based waiver services programs. These criteria differ from the assisted living licensing criteria but there is considerable overlap. Only a few states do not allow anyone who meets the nursing home level of care criteria to be served in an

assisted living facility.

State level of care criteria fit into four primary categories:

- Medical conditions or needs;
- A combination of medical conditions/needs and functional impairments;
- Functional impairment alone; and
- Scores from an assessment instrument.

Of the 45 states whose criteria were received for a 2002 study by the National Academy for State Health Policy, two used medical criteria; 13 used a combination of medical and functional criteria; 22 used ADL thresholds, and 8 based their decision on the assessment score. One used professional judgment, and one used a physician's statement.

Assessment score approaches included a mix of medical/functional and functional assessment items.

States can be arrayed along a continuum from low to high need thresholds for nursing home admission. (See Table). Admissions based solely on impairments in one or two of five to six ADLs are on the low end of the spectrum, those based on ADLs and medical criteria in the middle, and medical criteria on the high end. The placement of states within this continuum is somewhat arbitrary, and that the actual application of the criteria may be somewhat stricter or more lenient than placement within these categories suggest.

You can see that any statement about nursing eligible residents and assisted living means something very different depending on the particular state you are discussing. It would be clearer to talk about the needs, conditions and functional abilities of residents in relation to the services and staff available to serve them in an assisted living facility than whether they could be in a nursing home. After all, people can receive a very high level of care in their own homes.

Array of Selected States Along Continuum of Nursing Home Admission						
Criteria						
1 (low)	2	3 (moderate)	4	5 (high)		
CA	AR	MS	AK	MO	AZ	AL
DE	IL	NE	CO	MT	NC	HI
KS	IA	OK	CT	NJ	UT	ME
NH	IN	TX	FL	NM		MD
OH	LA	VT	GA	ND		TN
OR	MI	WI	ID	PA		VA
RI	MN		MA	SC		
WA						
WY						

Recommendations addressing the pre-screening process, move out requirement, medication storage, and special care facilities were considered too vague by several groups. These limitations could be addressed by states that may want to specify how an area is addressed such as who conducts the pre-screening assessment and how it is used.

The move out recommendation raises the question of whether facilities may or are required to provide all the services allowed by regulation. As long as facilities with a higher license are able to serve residents who have lower levels of need, aging in place can be accommodated. States that license by level of care may allow or require that the services be available or simply state the staffing requirements for residents based on their ability to evacuate in an emergency. Permissive admission criteria allow facilities the flexibility of establishing a policy based on its business plan, mission, staffing patterns, the skills of the staff and the availability of nursing expertise.

General licensing criteria lead to variations in the needs of residents who will be served, the services provided to meet those needs, patterns, and the skills of staff. In these instances, the resident agreement or contract is the vehicle for describing who will be served, what services will be provided and when a person may be asked to move.

Recommendations for special care facilities included general descriptions of areas that would be addressed by facility policy, such as staff training, policies, and procedures. Several members of the Workgroup felt the statements were too vague. In 2002, thirty-six states had provisions for facilities serving residents with Alzheimer's disease or dementia, an increase from 28 in 2000. These provisions addressed the philosophy of care, disclosure, staffing patterns and training, activities, the physical environment, family involvement and the cost of services.

The staff training requirement for special care facilities did not specify the hours of training, the topics to be covered or a required curriculum. However, the list does help identify what is important and serves as the minimum threshold. Specific provisions are easier for facilities to implement and for oversight agencies to measure. General provisions give facilities flexibility to vary training based on the resident population, and accessibility to training resources especially in rural areas. They require that oversight staff review each facility's policies and procedures and make a determination about their appropriateness. Again, state rules for staff training in special care facilities vary. Many specify the number of hours, topics for training or both. Arizona requires that 12 of 75 hours initial training cover dementia and 4 hours per year of ongoing training. Florida requires 8 hours of initial training and 4 hours per year. Maine's rules require 8 hours of classroom training and 8 hours of clinical training. Texas requires 4 hours of training and 16 hours of on the job supervision plus 12 hours annual in-service. Given these variations, it is difficult to determine what number of hours is most effective but they set a baseline on which future changes based on experience can be made.

The recommendations support the ability of aides who have completed training to administer medications. The recommendation is consistent with directions in state policy. The NASHP 2002 licensing survey found that sixty-four percent of the states allow aides who have completed and passed a training to administer medications. Ninety-eight percent allow aides to assist with self-administration. Thirty-three percent of responding states require facilities to have a consulting pharmacist. Several additional states require review of medications by a registered nurse.

Affordability

The report contains some excellent discussion of the barriers to the expansion of affordable assisted living facilities. Opposition to the recommendations was based on disagreement with the regulatory sections and questions about the universal description of assisted living as a less restrictive alternative to a nursing home. Affordable housing programs (low income housing tax credits, HUD's 202 program) are now being asked to support a product that was not envisioned when these programs were established. Currently, less than 15% of assisted living residents are low income while the percentage of low income nursing home residents is far higher. If assisted living is to be a viable option for low income tenants, federal policymakers need to consider the changes outlined in the report.

Another barrier is the amount of income available to pay for room and board. Medicaid waiver beneficiaries in many states have income that exceeds the SSI payment and therefore, depending on state policy, have more income that can be used to cover room and board. However, many do not. Beneficiaries who rely on the federal SSI benefit may not have sufficient income to cover room and board, especially in areas with high construction costs. The recommendations would support the ability of families to contribute to room and board costs, while the supplemental position opposes family contributions based on existing Medicaid rules. In 2002, about 19 states permitted family supplementation for room and board costs. Supplementation is not allowed for services covered by Medicaid. Since Medicaid does not pay for room and board, there are no federal prohibitions against supplementation. There is also concern that family supplementation means people with families who have resources will have access and those that do not will have less access. Family supplementation does reduce barriers for some. However, full access can only be obtained by expanding affordable assisted living or increasing the SSI payment for this setting. Covering room and board under Medicaid does not seem like a reasonable strategy since it would trigger a reduction in the federal SSI payment to the personal needs allowance for people in institutions. In effect, this would shift costs to state Medicaid programs without increasing the amount available for room and board.

Next steps

Whether you agree or disagree with the recommendations, the report is an excellent tool to frame policy options and encourage discussion about change. The report creates opportunities for members of the Workgroup to continue the process. There are clearly two distinct approaches to regulating assisted living. It would be useful for the groups who support the recommendations, and those who would offer an alternative, to develop a set of regulations that implements each approach. A detailed set of side-by-side "model regulations" could be prepared as the next step. It seems clear that stakeholders are not likely to reach full agreement about how assisted living should be regulated. What they can do is develop resources and information that informs the policy development process.

The Workgroup also recognized the need for more work to develop outcomes measures, update the recommendations, develop practice protocols, provide technical assistance to states upon request and other tasks. An additional function could be research on the impact of different regulatory approaches and requirements to see how different regulatory approaches affect outcomes. We do not have data to decide whether levels of care or general licensing guidelines work best. We don't know if regulations based on a philosophy of care produce different outcomes than regulations that do not. Research on assisted living in relation to regulatory requirements is limited and more is needed.

The proposed Center for Excellence is one way to address those needs. However, a group of members questioned whether the Center would be independent and that it might take over the role of government. Individually, states are not likely to have the resources to fund these activities. It may be possible to build a partnership between the federal government, states and a consortium of research organizations to carry out these functions. The consortium might be guided by an advisory board of stakeholders but would not be governed by them. DHHS' Office of the Assistant Secretary for Planning and Evaluation, which has funded research on assisted living in the past, might be an appropriate agency to fund this activity.

The report needs to be disseminated widely to state leaders – legislators, governors, commissioners, regulatory officials – as well as consumers, providers and professional organizations, to bring the discussion to the state level. I believe that the report will be a valuable document for stakeholders at the state level as they continue to refine and develop standards that support quality care for people who need assistance and prefer a residential environment. The Assisted Living Workgroup completed a difficult and ambitious task, requiring an enormous amount of time and work. The commitment and interest of the members of this Committee has certainly advanced our understanding of assisted living, and the different opinions about how it should be regulated.

Thank you.